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IN THE

Supreme Court of the United States

OCTOBER TERM, 1989

NANCY BETH CRUZAN, BY HER PARENTS AND CO-GUARDIANS, LESTER L. AND JOYCE CRUZAN,

Petitioners,

v.

DIRECTOR OF MISSOURI DEPARTMENT OF HEALTH, AND ADMINISTRATOR OF THE MISSOURI REHABILITATION CENTER AT MT. VERNON,

Respondents,

v.

THAD C. MCCANSE, GUARDIAN AD LITEM,

Respondent.

On Writ of Certiorari to the Missouri Supreme Court

BRIEF OF THE AMERICAN HOSPITAL ASSOCIATION AS AMICUS CURIAE IN SUPPORT OF PETITIONERS

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INTEREST OF THE *AMICUS CURIAE*

Amicus curiae, the American Hospital Association (AHA), respectfully submits this brief in support of the Petitioners. The AHA has obtained the written consent of both the

Petitioners and the Respondents to the filing of this brief *amicus curiae*.[1]

Founded in 1898, the AHA is the primary organization of hospitals in the United States. Its membership includes 71% of the nation's 7,051 hospitals, and 81% of the nation's 1,265,967 hospital beds.[2] Forty-eight thousand health care professionals hold individual membership in the AHA.

The AHA's corporate mission is to promote the quality of American health care and health services for all people through leadership and assistance to hospitals and health care organizations. To fulfill this mission, AHA regularly participates in important issues in the judicial and legislative arena.

The AHA has played a leadership role in the ongoing debate concerning biomedical ethical issues. Through its Special Committee on Biomedical Ethics, the AHA has published policies and positions addressing the role of patients, families, guardians, physicians and hospitals involving the withholding and withdrawal of medical treatment. Further, the AHA's bimonthly publication, *Hospital Ethics*, offers a forum for learned discussion of biomedical ethical issues.

As a leader in the health care field, as the representative of those institutions where the withholding and withdrawal of treatment occurs and as a contributor to the biomedical ethical debate, the AHA is vitally concerned about the heightened anguish, time and expense which will be forced upon patients, families, providers and society should the opinion and reasoning of the Missouri Supreme Court be affirmed.

SUMMARY OF ARGUMENT

Everyday in American hospitals thousands of decisions to forego life-sustaining medical treatment are made. These

[1]The letters providing consent from all parties have been filed with the Clerk of the Court.

[2]AHA, *Hospital Statistics* (1988).

decisions are arrived at within a collaborative relationship among patients, families, physicians and institutions. Hospital policies and procedures foster this time-honored process in an informed, compassionate and ethical manner, obviating the necessity for constant judicial scrutiny.

The American Hospital Association submits that the past pronouncements of this Court respect the rights of patients, families and health care providers to participate in this most sacred of human decisions.

ARGUMENT

Approximately 2.2 million Americans die each year.[3] One million three hundred thousand of these people die in hospitals.[4] Seventy percent die after a decision to forego life-sustaining treatment has been made.[5]

The plight of Nancy Beth Cruzan is indeed tragic, but it is not unique. Decisions to forego life-sustaining medical treatment are made in this nation's hospitals every day. Almost all of these decisions are made privately by the patient, family and physician. It is the rare case that surfaces in the public domain.

Informed, compassionate, ethical decisionmaking routinely occurs at the institutional level. This Court should reject the Missouri Supreme Court's invitation for constant judicial involvement in medical treatment decisions.

[3]United States National Center for Health Statistics, 37 Monthly Vital Statistics 6 (1989).

[4]United States National Center for Health Statistics, *Vital Statistics of the United States* (1986).

[5]Lipton, McNamee and Campion, *Do-Not-Resuscitate Decisions in a Community Hospital: Incidence, Implications and Outcomes*, 256 JAMA 1164 (1986).

I. THE AMERICAN HOSPITAL ASSOCIATION'S POLICIES AND PROTOCOLS ON MEDICAL DECISIONMAKING ARE DEEPLY ROOTED IN RESPECT FOR INDIVIDUAL AUTONOMY.

In 1972, the American Hospital Association's Board of Trustees approved its policy statement on *A Patient's Bill of Rights* and in February and April of 1985 the Board approved respectively the works of its Special Committee on Biomedical Ethics entitled *Patient's Choice of Treatment Options*, App. *infra*, A., B., and *Values in Conflict: Resolving Ethical Issues in Hospital Care*.[6]

Under these policies, the patient's role as the focal point of medical decisionmaking must be ensured in the institutional setting. Although these decisions should be made in collaboration with the attending physician, the hospital must take a leadership role by establishing institutional practices that support patient decisionmaking and identify when recourse to the judgment of others is necessary.

The foundation of these policy principles is consonant with pronouncements of this Court, which as early as 1891 affirmed that individuals are sovereign over their own persons: "No right is held more sacred, or is more carefully guarded, by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law." *Union Pacific Railway Company v. Botsford*, 141 U.S. 250, 251 (1891).

More recently, this Court has characterized this principle of self determination as a liberty interest protected by

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[6]AHA Policy: *A Patient's Bill of Rights* (1972); AHA Policy and Statement: *Patient's Choice of Treatment Options* (1985); AHA, *Values in Conflict: Resolving Ethical Issues in Hospital Care* (1985). Portions of these American Hospital Association policies are reproduced in the Appendix of this Brief.

the Due Process Clause of the Fourteenth Amendment and as a privacy right which springs from the protections under the Bill of Rights. *See Griswold v. Connecticut*, 381 U.S. 479 (1965); *Eisenstadt v. Baird*, 405 U.S. 438 (1972); *Roe v. Wade*, 410 U.S. 113 (1973); *Doe v. Bolton*, 410 U.S. 179 (1973); *Parham, Commissioner, Department of Human Resources of Georgia v. J.R.*, 442 U.S. 584 (1979); and *Youngberg v. Romeo*, 457 U.S. 307 (1982).

While this Court has not directly addressed an individual's constitutional right to refuse life-prolonging medical treatments,[7] since the New Jersey Supreme Court's seminal decision concerning the plight of Karen Ann Quinlan, *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, *cert. denied*. 429 U.S. 922 (1976), numerous state courts have affirmed the prerogatives reflected in the American Hospital Association's commitment to respect for patient decisions.[8]

Citing this Court and specific articles of the New Jersey constitution, the *Quinlan* court held: "Presumably this right is broad enough to encompass a patient's decision to decline medical treatment under certain circumstances, in much the same way as it is broad enough to encompass a woman's decision to terminate pregnancy under certain circumstances." *Quinlan*, 70 N.J. at 40.

Furthermore, forty states and the District of Columbia have enacted so-called "living will" statutes which foster the exercise of the fundamental right to order one's medical liber-

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[7]*Gray v. Romeo*, 697 F. Supp. 580 (D.R.I. 1988), upheld the federal constitutional right of an incompetent patient to forego the artificial provision of nutrition and hydration. No appeal was taken.

[8]Ironically, while denying these decisional prerogatives to Nancy Cruzan, the Missouri Supreme Court ably catalogues over 50 cases in 16 states which vindicate the treatment elections of the Cruzan family. *Cruzan, by Cruzan v. Harmon*, 760 S.W.2d 408, 412-413 n.4 (Mo. banc. 1988).

ties.[9] Such initiatives countenance recognition and vindication of individual treatment choices which form the core of the American Hospital Association's long standing policies respecting individual medical decisionmaking: ". . . the authority to determine the course of treatment, if any, should rest with the patient . . . . The right to choose treatment includes the right to refuse a specific treatment or all treatment, or select an alternative form of treatment. AHA Policy and Statement: *Patient's Choice of Treatment Options* (1985). App. *infra*, B.

Accordingly, the principle that competent individuals are sovereign over their own persons and can ordain the disposition of their bodies is widely recognized. The members of the American Hospital Association routinely rely upon this fundamental maxim when providing care to all patients.

II. THE AMERICAN HOSPITAL ASSOCIATION BELIEVES THAT TREATMENT DECISIONS FOR PATIENTS LACKING DECISIONMAKING CAPACITY SHOULD BE MADE AT THE INSTITUTIONAL LEVEL BY THE FAMILY IN CONSULTATION WITH HEALTH CARE PROVIDERS

A. Families Are Presumptively The Appropriate Locus Of Medical Treatment Decisions For Patients Lacking Decisionmaking Capacity.

The right of self determination vouchsafed to a competent patient can and should be exercised by that patient's family should the patient lack decisionmaking capacity.[10] The policies and protocols of the American Hospital Association

[9]For a list of these states *see In re Farrell*, 108 N.J. 335, 342 n.2, 529 A.2d 404, 407 n.2 (1987).

[10]The AHA believes that "family" includes those related by blood or marriage, as well as friends and loved ones as recognized under state law.

contend that those in a position to know and appreciate the totality of an incompetent person's approach to life are the ones who should be entrusted with decisionmaking power in their regard.[11] The AHA submits that it is the family who is most able to advocate the patient's wishes and to assess the patient's purposes and experiences.

Throughout history it has been the family's duty and responsibility to attend to the sick and dying. Death was primarily a private matter which occurred in the confines of the home. With the development of health care institutions and modern medical technology, the situs of death has shifted from the home to the institution.[12] Yet it was, and will continue to be, the family which remains the primary source of comfort for the dying individual.

This Court has long recognized the family as the appropriate surrogate on behalf of its members lacking decisionmaking capacity. The right of the family to make fundamental decisions affecting the lives of its members received initial acceptance in *Meyer v. Nebraska*, 262 U.S. 390 (1923). Two years later, in *Pierce v. Society of Sisters*, 268 U.S. 501, 535 (1925), this Court, citing the *Meyer* decision, reaffirmed the constitutional notion of a family's duties and obligations to exercise rights on behalf of their incompetent own: "The child is not the mere creature of the State; those who nurture him and direct his destiny have the right, coupled with the high duty, to recognize and prepare him for additional obligations."

[11]Patient's prior directives, whether written or oral should, of course, be heeded. Where conflict exists concerning these directives, recourse to institutional or judicial review would be appropriate. *See* AHA Policy and Statement: *Patient's Choice of Treatment Options* (1985). App. *infra*, B.

[12]*See* President's Commission for The Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment* 17 (1983).

More recently, in *Parham, Commissioner, Department of Human Resources of Georgia v. J.R.*, 442 U.S. 584, 602 (1979), the Court stressed the historical ". . . concepts of the family as a unit with broad parental authority over minor children," and the recognition ". . . that the natural bonds of affection lead parents to act in the best interest of their children" when they must be hospitalized for psychiatric care. This same Court further interpreted past precedents in favor of a presumption that parents should be able to make decisions regarding the medical treatment of their children: "[W]e conclude that our precedents permit the parent to retain a substantial, if not dominant, role in the decision, absent a finding of neglect or abuse, and that the traditional presumption that the parents act in the best interests of their child should apply." *Parham*, 442 U.S. 604.[13]

As in *Parham*, this Court in *Michael H. and Victoria D. v. Gerald D.*, 109 S.Ct. 2333, 2342 (1989), again underscored the time-honored trust and respect reposed in the American family: ". . . sanctity would not be too strong a term–traditionally accorded to the relationships that develop within the unitary family."

Building upon these foregoing principles, state supreme courts have generally embraced the notion that family members of patients lacking decisionmaking capacity are the proper parties to make substituted medical judgments on their behalf. The New Jersey Supreme Court fairly reflects the evolving national consensus:

> Family members are best qualified to make substituted judgments for incompetent patients not only because of their peculiar grasp of the patient's approach to life, but

[13]The wisdom of the Court's description of the parent's powerful role in making decisions for children who lack decisionmaking capacity due to age, is no less apt for the present situation where Nancy Cruzan's parents wish to make a decision for their child lacking decisionmaking capacity due to illness.

> also because of their special bonds with him or her. Our common human experience informs us that family members are generally most concerned with the welfare of a patient. It is they who provide for the patient's comfort, care and best interests . . ., and they who treat the patient as a person, rather than a symbol of a cause . . . . We believe that a family member is generally the best choice [to make medical treatment decisions].

In re Jobes, 108 N.J. 394, 415-416, 529 A.2d 434, 445 (1987) (*quoting* Newman, *Treatment Refusals for the Critically Ill: Proposed Rules for the Family, the Physician and the State*, III N.Y.L. Sch. Human Rights Annual, Part One 45-46 (1985)).

Indeed, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research in *Deciding to Forego Life-Sustaining Treatment* (1983), the Hastings Center in *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying* (1987), the Congress of the United States Office of Technology Assessment in *Life-Sustaining Technologies and the Elderly* (1987), The New York State Task Force on Life and the Law in *Life-Sustaining Treatment: Making Decisions and Appointing a Health Care Agent*, Professor Rhoden in *Litigating Life and Death*, 102 Harv. L. Rev. 375 (1988), Professor Newman in *Treatment Refusals for the Critically Ill: Proposed Rules for the Family, the Physician and the State*, III N.Y.L. Sch. Human Rights Annual, Part One (1985) and the National Conference of Commissioners on Uniform State Laws in the *Uniform Rights of the Terminally Ill Act* (1985) have all affirmed the fundamental belief in the integrity of the family, physician and the institution as proper cooperators in the necessarily difficult decisions concerning patients lacking decisionmaking capacity.

Support for the family as a surrogate decisionmaker for patients lacking decisionmaking capacity abounds as well in the medical literature. Not only is the importance of family paramount, but physicians are encouraged to involve them

early in decisions concerning the withholding and withdrawal of medical treatment for such patients. Ruark, Raffin, and the Stanford University Medical Center Committee on Ethics, *Initiating and Withdrawing Life Support,* 318 New Eng. J. Med. 25 (1988). *See also* Carlson, Devich and Frank, *Development of a Comprehensive Supportive Care Team for the Hopelessly Ill on a University Hospital Medical Service,* 259 JAMA 378 (1988).

Empirical support for the acceptance of the family as the primary community of decisionmaking is to be found in a recent study which concluded that families, in collaboration with health care providers, make decisions which best reflect treatment elections made by patients themselves: "We believe the result of our study is reassuring and indicates that substitute judgement is used wisely. There is no difference in any important aspect between the competent patients who decide to stop dialysis and die and the incompetent patients for whom the decision is made by someone else." Silva and Kjellstrand, *Withdrawing Life Support: Do Families and Physicians Decide as Patients Do?,* 48 Nephron 201, 204 (1988). *See also* Neu and Kjellstrand, *Stopping Long-Term Dialysis,* 314 New Eng. J. Med. 14 (1986).

The AHA has consistently supported a continuing faith in the traditional decisionmaking framework, allowing for the exercise of individual treatment decisions on behalf of patients lacking decisionmaking capacity by those who know and love the patient most dearly–the family.

> [T]he best substitute for an incapacitated patient is a surrogate who can take action consistent with the previously expressed or known wishes of the patient .... If the patient has never designated a surrogate, then health care professionals should work together to find family members who are in a position to know what the incapacitated patient would have wanted to do in the situation at hand.

AHA, *Legal Memorandum Number Nine–Discharging Hospital Patients: Legal Implications for Institutional Providers and Health Care Professionals* 12-13 (1987).

Thus, the legal, medical and scholarly communities recognize that medical treatment decisions should be exercised by the family, on behalf of patients lacking decisionmaking capacity. Every day, in the nation's hospitals, family treatment choices reflect informed, compassionate and ethical decisionmaking.

B. Treatment Decisions Made By The Family Occur In Collaboration With Health Care Providers.

Notwithstanding the primary role of the family in making treatment choices for their incapacitated loved ones, individual treatment decisions are never made in isolation. Rather, decisionmaking is based on a collaborative relationship among the family, physician and other health care professionals who are primarily responsible for the patient's care. Institutional policies and procedures also foster the decisionmaking process, assuring that decisions to withhold or withdraw medical treatment are structured to respect patient and family wishes within the bounds of medical, ethical and legal confines. This collaborative process is the cornerstone of medical decisionmaking in hospitals across the land.

1. *The Responsibility For Assuring The Integrity Of Medical Decisionmaking Falls First To The Attending Physician.*

As health care providers and as architects of the patient care plan, physicians bear the primary responsibility for assuring that family decisionmaking is the product of an informed judgment premised upon sound medical and ethical prescriptions.

Physicians fulfill this role within the accepted doctrines

of the physician-patient relationship and informed consent to medical treatments. *Canterbury v. Spence*, 464 F.2d 772 (D.C. Cir.), *cert. denied*, 409 U.S. 1064 (1972).

Within the physician-patient relationship, physicians have a legal and ethical duty to the patient to ensure that treatment decisions are made which foster and protect the patient's best interests. *See* American Medical Association, *Current Opinions of the Council on Ethical and Judicial Affairs of the American Medical Association*, Opinion 2.18 (1986). This duty does not end once a patient lacks decisionmaking capacity – the physician maintains his obligations and allegiance to the patient.[14] The physician-patient relationship, therefore, plays a critical role in guarding the patient from surrogate treatment decisions which are inconsistent with sound medical practice and ethical conduct.

Central to the safeguards of the decisionmaking process among the patient, family and physician is the notion of informed consent. Generally, there are three basic prerequisites for informed consent: (1) The patient must have the capacity to reasonably make judgments; (2) the patient must have a clear understanding of the nature of the disease and his prognosis, as well as the risks and benefits of the proposed treatment alternatives; and (3) the decision must be made voluntarily and without coercion. Applebaum and Grisso, *Assessing Patients' Capacities to Consent to Treatment,* 319 New Eng. J. Med. 1635 (1988).

Ordinarily, the patient's decisionmaking capacity is presumed unless questions arise concerning the patient's cognitive processes. In such instances, it is the physician's duty to make an assessment of the patient's decisionmaking capacity before accepting any decision about medical care. *Presi-*

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[14]Physicians, of course, are under a continuing duty to honor the incapacitated patient's previously expressed desires regarding the use of life support. In some cases, living wills or durable powers of attorney or other statements may help to clarify these desires.

dent's Commission at 45. If a patient is found to have decisionmaking capacity, the patient's judgments will be honored. To foster this protective process, only in those instances where a patient is found to lack such capacity will the physician turn to the family for a treatment decision.[15]

To ensure that families have a clear understanding of the nature of the disease and the risks and benefits of proposed treatments, the physician must provide them with the diagnosis, possible courses of treatment, all material risks of the treatment options including the degree of hazard of each choice, and the benefits and disadvantages of the various treatment elections as well as the risk and benefit of nontreatment. *See* Wanzer, *et al.*, *A Physician's Responsibility Toward Hopelessly Ill Patients,* 310 New Eng. J. Med. 955 (1984); Applebaum and Grisso, *Assessing Patients' Capacities to Consent to Treatment,* 319 New Eng. J. Med. 1635 (1988). This information protects patients by assuring that treatment decisions are grounded in sound medical advice.

Finally, a family's treatment choice should be uninfluenced by coercion. It is the role of the physician to assist the family in making treatment decisions which are medically warranted for that patient. American Medical Association, *Current Opinions of the Council on Ethical and Judicial Affairs of the American Medical Association*, Opinions 2.18, 2.19 (1986).

Physicians collaborate with families in making treatment decisions. Through the physician-patient relationship and the doctrine of informed consent, the physician assists the fam-

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[15]These determinations are generally made without resort to any formal legal process. When an incapacitated patient lacks any close family members or friends, or when the determination regarding decisionmaking capacity is controversial among concerned persons (including the patient), legal guardianship proceedings may be considered. *See* AHA Policy and Statement: *Patient's Choice of Treatment Options* (1985). App. *infra*, B.

ily in assuring that treatment decisions for patients lacking decisionmaking capacity are respectful of patient sovereignty and are in keeping with accepted medical, ethical and legal principles. *See* AHA Policy: *A Patient's Bill of Rights* (1972). App. *infra*, A.

2. *Hospitals Play An Important Role In Fostering And Guiding Medical Decisionmaking.*

While the physician is responsible for advising the patient and family and supervising the course of treatment, the hospital, through its institutional policies, plays an important role in fostering and guiding medical decisionmaking. Further, through its staff and available institutional advisory mechanisms, such as ethics committees, the hospital strives to ensure the integrity of decisionmaking about life-sustaining treatment.[16]

Hospital policies and procedures constitute important safeguards for the decisionmaking process. First, hospital policies establish a framework for determining a patient's decisionmaking capacity.[17] The American Hospital Association's Policy and Statement on *Patient's Choice of Treatment Options*, App. *infra*, B., states that institutions should have effective policies to facilitate assessment of patients' decisionmaking capacity. Specifically, the institution should have methods to ensure that the physician conducts these assessments when necessary. The hospital should also see to it that there are accessible and practical avenues by which concerns about a patient's capacity to make decisions may be raised

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[16]*See* AHA Guidelines: *Hospital Committees on Biomedical Ethics* (1984). App. *infra*, D.

[17]The actual determination of decisionmaking capacity is made by the physician relying upon his or her medical judgment. AHA, *Values in Conflict: Resolving Ethical Issues in Hospital Care* 16 (1985).

by others, including family, friends, nurses and other health care professionals.

Second, hospitals employ policies governing the obtaining of informed consent. These policies are required by the Joint Commission on Accreditation of Health Care Organizations (JCAHO) and, by reference, the federal Medicare program. JCAHO, *Accreditation Manual for Hospitals*, Medical Record Services Standard MR. 2.2.71 at 91 (1989); 42 U.S.C. §1395bb(a)(1)(1989).[18] These JCAHO standards require that the medical record contain evidence that informed consent has been obtained for procedures and treatments under these informed consent policies. In daily practice, hospitals provide for the documentation of such informed consent.

The AHA is supportive of hospitals maintaining policies to assure the obtaining of informed consent. In its Guidelines entitled *Ethical Conduct for Health Care Institutions* (1987), App. *infra*, C. , the AHA states that health care institutions should have policies and practices that support the process of informed consent for diagnostic and therapeutic procedures and that respect and promote the patient's responsibility for decisionmaking.

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[18]JCAHO, formerly the Joint Commission on Accreditation of Hospitals, is a private, voluntary, accrediting body whose basic purposes are to establish standards for the operation of health care facilities, to conduct survey and accreditation programs that encourage and assist health care facilities in the task of promoting efficient, high quality patient care, and to recognize compliance with their standards by issuance of certificates of accreditation. JCAHO has five member organizations which appoint commissioners to its Board: American Hospital Association, American Medical Association, American College of Surgeons, American College of Physicians and the American Dental Association. An additional commissioner is appointed by the Board from the general public. Many states also accept JCAHO accreditation as evidence of compliance with their own licensing standards.

Third, hospital policies governing the withholding and withdrawal of medical treatment also safeguard the decision-making process.[19] These policies typically provide a framework for making treatment decisions for incompetent patients, including identification of procedures for securing informed consent, determination of surrogates, guidelines for documenting the withholding or withdrawal of treatment, as well as detailing when recourse to available institutional advisory mechanisms is appropriate. *See generally* AHA Policy and Statement: *Patient's Choice of Treatment Options* (1985). App. *infra*, B.

Finally, hospital policies set forth procedures to determine appropriate surrogate decisionmakers. While the content of these policies varies due to state law and institutional characteristics (such as religious affiliation), the policies are often quite specific as to the determination of the appropriate surrogate.

Thus, nationwide, hospitals have historically developed and maintained protocols to enhance decisionmaking by families and physicians. These policies have clearly and effectively provided for compassionate treatment decisions on a daily basis with the rare need to seek judicial review.

CONCLUSION

Decisions to forego or withhold life-sustaining medical treatment are made on a daily basis in hospitals and other health care institutions throughout this country. The American Hospital Association believes that the existing institutional-based procedures for making these decisions for patients lack-

[19]Since January 1988, all hospitals have been required to develop written policies governing the withholding of resuscitative services from patients. JCAHO, *Accreditation Manual for Hospitals*, Management and Administrative Services Standard MA.1.4.11 at 82 (1989).

ing decisionmaking capacity adequately ensure that they are made with care, dignity and respect for patient sovereignty.

The policies of the AHA strive to foster individual, familial and surrogate decisionmaking within the longstanding framework of the physician-patient relationship and the informed consent doctrine. Required judicial involvement, flowing from the decision of the Missouri Supreme Court, would wreak havoc on this time-honored process which has served patients, families and health care providers well.

Accordingly, the American Hospital Association, as Friend of the Court, respectfully urges this Court, for all the foregoing reasons, to reverse the majority decision of the Missouri Supreme Court.

Respectfully submitted,

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1 September 1989

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APPENDIX

APPENDIX A

AMERICAN HOSPITAL ASSOCIATION

Policy

A PATIENT'S BILL OF RIGHTS

This policy document presents the official position of the American Hospital Association as approved by the Board of Trustees and House of Delegates.

The American Hospital Association presents A Patient's Bill of Rights with the expectation that observance of these rights will contribute to more effective patient care and greater satisfaction for the patient, his physician, and the hospital organization. Further, the Association presents these rights in the expectation that they will be supported by the hospital on behalf of its patients, as an integral part of the healing process. It is recognized that a personal relationship between the physician and the patient is essential for the provision of proper medical care. The traditional physician-patient relationship takes on a new dimension when care is rendered within an organizational structure. Legal precedent has established that the institution itself also has a responsibility to the patient. It is in recognition of these factors that these rights are affirmed.

During the 1970s the American Hospital Association's Board of Trustees had a Committee on Health Care for the Disadvantaged, which developed the *Statement on a Patient's Bill of Rights.* That document was approved by the AHA House of Delegates on February 6, 1973, and has been published in various forms. This reprinting and reclassification conforms with the current classification system for AHA documents. The contents are unchanged.

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1. The patient has the right to considerate and respectful care.

2. The patient has the right to obtain from his physician complete current information concerning his diagnosis, treatment, and prognosis in terms the patient can be reasonably expected to understand. When it is not medically advisable to give such information to the patient, the information should be made available to an appropriate person in his behalf. He has the right to know, by name, the physician responsible for coordinating his care.

3. The patient has the right to receive from his physician information necessary to give informed consent prior to the start of any procedure and/or treatment. Except in emergencies, such information for informed consent should include but not necessarily be limited to the specific procedure and/or treatment, the medically significant risks involved, and the probable duration of incapacitation. Where medically significant alternatives for care or treatment exist, or when the patient requests information concerning medical alternatives, the patient has the right to such information. The patient also has the right to know the name of the person responsible for the procedures and/or treatment.

4. The patient has the right to refuse treatment to the extent permitted by law and to be informed of the medical consequences of his action.

5. The patient has the right to every consideration of his privacy concerning his own medical care program. Case discussion, consultation, examination, and treatment are confidential and should be conducted discreetly. Those not directly involved in his care must have the permission of the patient to be present.

6. The patient has the right to expect that all communications and records pertaining to his care should be treated as confidential.

7. The patient has the right to expect that within its capacity a hospital must make reasonable response to the request of a patient for services. The hospital must provide evaluation, service, and/or referral as indicated by the urgency of the case. When medically permissible, a patient may be transferred to another facility only after he has received complete information and explanation concerning the need for and alternatives to such a transfer. The institution to which the patient is to be tranferred must first have accepted the patient for transfer.

8. The patient has the right to obtain information as to any relationship of his hospital to other health care and educational institutions insofar as his care is concerned. The patient has the right to obtain information as to the existence of any professional relationships among individuals, by name, who are treating him.

9. The patient has the right to be advised if the hospital proposes to engage in or perform human experimentation affecting his care or treatment. The patient has the right to refuse to participate in such research projects.

10. The patient has the right to expect reasonable continuity of care. He has the right to know in advance what appointment times and physicians are available and where. The patient has the right to expect that the hospital will provide a mechanism whereby he is informed by his physician or a delegate of the physician of the patient's continuing health care requirements following discharge.

11. The patient has the right to examine and receive an explanation of his bill regardless of source of payment.

12. The patient has the right to know what hospital rules and regulations apply to his conduct as a patient.

No catalog of rights can guarantee for the patient the kind of treatment he has a right to expect. A hospital has many functions to perform, including the prevention and treatment of disease, the education of both health professionals and patients, and the conduct of clinical research. All these activities must be conducted with an overriding concern for the patient, and, above all, the recognition of his dignity as a human being. Success in achieving this recognition assures success in the defense of the rights of the patient.

APPENDIX B

AMERICAN HOSPITAL ASSOCIATION

Policy and Statement

PATIENT'S CHOICE OF TREATMENT OPTIONS

POLICY

Health care decision making should be based on a collaborative relationship between the patient and the physician and/or other health care professionals who are primarily responsible for the patient's care.* The collaborative framework encourages communciation, which contributes to sound decision making. Whenever possible, however, the authority to determine the course of treatment, if any, should rest with the patient, who may choose to delegate it. In the hospital setting, institutional methods should be established to reasonably assure that the patient may exercise this authority on the basis of relevant information necessary to make a sufficiently voluntary and informed decision. In addition, the health care institution should have methods to identify

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*The term *physician* is used throughout the document, although other health care professionals may be responsible for or authorized to provide patient care.

This policy and statement was developed by the Special Committee on Biomedical Ethics, which had been established by the General Council in January 1983 to consider various aspects of biomedical ethical issues facing the health care field.

This document replaces the *Guidelines on the Right of the Patient to Refuse Treatment* that was approved in 1973. The House of Delegates approved the policy and statement in February 1985.

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circumstances under which the patient's authority may be constrained, and recourse to the judgment of others, including the courts, is appropriate.

STATEMENT

The right and responsibility to select among treatment options** presumes that the patient is capable of consulting with the physician about and understanding the available treatment alternatives and their implications and making a choice. Consultation might also take place with other responsible or authorized health care professionals involved in coordinating the patient's care. This process requires the patient's adequately-informed consent and may involve an evaluation of the patient's capacity to make a decision.

Collaborative Decision-Making

Informed consent should reflect shared or collaborative decision making by the patient and the physician. The physician should provide information on the patient's condition, the recommended procedure and/or treatment with its significant benefits and risks, the significant alternative for care or treatment (including no specific treatment), and the likely duration of incapacitation, if any.† Because patient's understanding of this information is essential to informed consent, care should be taken to present it in language familiar to them. Although institutional policy should promote documentation of consent decisions, such documentation is evidence of but not a substitute for communication and understanding between patient and physician. Unless the physician believes the patient would object, it may be advisable and

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**For the purpose of this document, treatment can be interpreted to include diagnostic as well as therapeutic procedures.

†See the AHA Policy on *A Patient's Bill of Rights.*

useful if this information is shared with the patient's family, which often is a valuable resource for both the patient and the physician. Health care institutions and professionals should see to it that patients have access to understandable information relevant to the treatment choices before them.

In cases where the patient has chosen to delegate the treatment choice selection to the physician or someone else, a discussion with the patient about the implications and ramifications of the treatment course to be pursued is still recommended. Often family and friends should be included in this discussion.

In some emergencies, obtaining voluntary and adequately informed consent may not be possible or may be detrimental to the patient's well-being. In such cases, the patient's consent to the course of treatment chosen by a physician may be legally implied from the urgent circumstances surrounding the provision of that care.

Implications of Treatment Choice

The right to choose treatment includes the right to refuse a specific treatment or all treatment, or select an alternative form of treatment. If the patient decides to refuse all treatment, a written informed refusal is strongly recommended to protect the hospital, the physicians, and all other personnel from liability, if any, for failure to furnish treatment. This decision should also be documented on the patient's chart.

If a patient chooses a course of treatment that is not acceptable to the attending physicians or other health care professionals, those individuals may withdraw from the case, so long as doing so does not amount to legal abandonment. If a suitably qualified alternative physician or health care professional willing to comply with the patient's preference is available, transfer to the care of that individual should be offered to the patient. If no physician or qualified health care

professional is willing to undertake the patient's choice of treatment, the hospital should have a policy to address what procedures relative to care of the patient should be followed. The hospital also should have a policy to help identify and address those situations when the course of treatment selected is unacceptable to the mission of the institution.

Laws regarding the right of a patient or someone on the patient's behalf to refuse treatment vary from state to state. Some state laws limit a patient's right to refuse treatment, and others make provisions to facilitate the exercise of this right. The hospital's and the physician's response to a refusal, whether action or nonaction, must be consistent with applicable law. If a refusal can potentially result in substantial detriment to the patient's health and well-being, institutions should require that the appropriate administrative authority be informed. Protection of the patient's authority to select treatment at times may require either legal counsel or judicial proceedings.

Decision-Making Capacity

Decision-making capacity is the ability to make choices that reflect an understanding and appreciation of the nature and consequences of one's actions. Attention should be paid to the difference between decision-making capacity and legal competency. Decision-making capacity may exist, as in the case of a minor, where no legal competency exists. Legal competency may exist where decision-making capacity does not, as in the case of a temporarily impaired adult who has not been deemed legally incompetent. In health care treatment decisions, decision-making capacity is best understood as the patient's ability to understand the nature and effects of treatment options, and appreciate the impact of a choice. Only when the patient's capacity to make decisions is definitely impaired and the effect of flawed decision making

is potentially serious should the patient's right and responsibility for decision making be transferred to others.

When there is reason to doubt the usual presumption of adequate decision-making capacity, an assessment of capacity is made by the physician in consultation with the family, friends, nurses, and other health care professionals. The institution should have effective policies to facilitate assessment of patients' decision-making capacity. The institution should have methods to ensure that the physician conducts these assessments when necessary. The hospital should also see to it that there are accessible and practical avenues by which concerns about a patient's capacity to make decisions may be raised by others, including family, friends, nurses, and other health care professionals. The hospital may also wish to have a policy under which a patient, in appropriate circumstances, should be informed both of any concerns raised by the assessment and of access to procedures for reassessment or to legal counsel. Only when the determination regarding decision-making capacity is controversial among concerned persons (including the patient) should legal guardianship proceedings be required.

When a patient lacks adequate decision-making capacity, substantial effort should be made to ensure that the choice of medical treatment is consistent with the known views of the patient. The decision makers must seek and take note of any information reflected in oral statements, life-style commitments, living wills, and so forth made by the patient before deterioration of decision-making capacity. These known views can sometimes be supplied by the family or an individual acting as surrogate. The surrogate should be a person or group of persons most likely to be able to advocate on the patient's behalf and to assess the patient's preferences and experiences. If the physician knows through informal communications, durable power of attorney, or living will of the patient's designation of a surrogate, that person should serve unless mitigating factors are apparent.

If the selection of the surrogate seems controversial, methods for institutional review and, if necessary, court adjudication are required. In some cases, court appointment of a surrogate may be legally required. The institution should be prepared to refer difficult cases to court for guardianship determinations.

Role of Minors in Decision-Making

Patients who are minors should be allowed to participate in decision-making about their care to the extent possible with regard to their capacity to understand treatment options and outcomes. When a minor is deemed legally incapable of making a decision, that is, not considered to be a "mature" or "emancipated" minor according to state law, the parent or legal guardian usually will have the final decision-making authority. Mature or emancipated minors, as determined by state law, should be treated as adults with decision-making capacity.

Institutions should establish policies concerning the circumstances under which legal advice is to be sought for either the institution or the minor, including cases where a parent or guardian makes a decision that may be deemed adverse to the interests of a minor or opposed to the expressed views of a relatively mature minor.

Management Practices and Procedures

Hospitals have a responsibility to assess the effect of management practices and procedures on patient decision-making options and to foster awareness among health care professionals and key hospital personnel that some institutional practices necessary to ensure efficiency, such as some admissions or food service procedures, can unintentionally limit patient choices. For example, the patient often does not have the opportunity to make many of the routine choices in day-to-day living–when to have meals, wake up, have visitors, etc.

Documentation of Decision-Making

Documentation of decisions regarding patient treatment promotes orderly procedures and more thorough consideration of options. Documentation also provides legal protection for and is often in the best interests of patients, patients' families, concerned health professionals, and hospitals.

Conclusion

The patients' role in determing the course of their medical treatment must be ensured in the institutional setting. Although these decisions should be made in collaboration with the attending physicians, the hospital must take a leadership role in ensuring institutional practices that support patients' decision making and in identifying when recourse to the judgment of others is necessary.

APPENDIX C

AMERICAN HOSPITAL ASSOCIATION

Guidelines

ETHICAL CONDUCT FOR HEALTH CARE INSTITUTIONS

Introduction

Health care institutions, by virtue of their roles as health care providers, employers, and community health resources, have special responsiblities for ethical conduct and practices. The broad range of patient care, education, public health, social service, and business functions they undertake are essential to the health and well-being of their communities. In general, there is a public expectation that they will conduct themselves in an ethical manner that emphasizes a basic community service orientation.

These guidelines are intended to assist members of the American Hospital Association to better define the ethical aspects and implications of institutional policies and practices. They are offered with the understanding that individual decisions seldom reflect an absolute ethical right or wrong, and that each institution's leadership in making policy

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This guideline document is intended to provide general advice to the membership of the American Hospital Association, as approved by the General Council.

These guidelines were developed by the AHA Advisory Committee on Biomedical Ethics and approved by the Board of Trustees in November 1987. They are considerably broader that the document that they replaced, *Guidelines on Ethical Conduct and Relationships for Health Care Institutions,* which was last revised in 1981.

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and decisions must take into account the needs and values of the institution, its medical community, and employees and those of individual patients, their families, and the community as a whole.

The governing board of the institution is responsible for establishing and periodically evaluating the ethical standards that guide institutional practices. The chief executive officer is responsible for assuring that hospital medical staff, employees, and volunteers and auxilians understand and adhere to these standards and for promoting an environment sensitive to differing values and conducive to ethical behavior.

These guidelines examine the hospital's ethical responsibilities to its community and patients as well as those deriving from its organizational roles as employer and a business entity. Although some responsibilities also may be included in legal and accreditation requirements, it should be remembered that legal, accreditation and ethical obligations often overlap and that ethical obligations often extend beyond legal and accreditation requirements.

Community Role

- Health care institutions should be concerned with the overall health status of their communities while continuing to provide direct patient services. This principle requires them to communicate and work with other health care and social agencies to improve the availability and provision of health promotion and education and services as well as patient care and to take a leadership role in enhancing public health and continuity of care in the community.

- Health care institutions are responsible for fair and effective use of available health care delivery resources to promote access to comprehensive and affordable health care services of high quality. This responsibility extends beyond the resources of the given institution to include efforts to

coordinate with other health care providers and to share in community solutions for providing care for the medically indigent and others.

- All health care institutions have community service responsibilities which may include care for the poor and the uninsured, provision of needed services and educational programs, and various programs designed to meet the specific needs of their communities. Not-for-profit institutions, in consideration of their community service origins, Hill-Burton obligations, and tax status, should be particularly sensitive to the importance of providing and designing services for their communities.

- Health care institutions, being dependent upon community confidence and support, are accountable to the public, and therefore their communications and disclosure of information and data related to the institution should be clear, accurate, and sufficiently complete to assure that it is not misleading. Such disclosure should be aimed primarily at better public understanding of health issues, the services available to prevent and treat illness, and patients' rights and responsibilities relating to health care decisions.

- As health care institutions operate in an increasingly competitive environment, they should consider the overall welfare of their communities and their own missions in determining their activities, service mixes, and business ventures and conduct their business activities in an ethical manner.

Patient Care

- Health care institutions are responsible for assuring that the care provided to each patient is appropriate and of the highest quality they are able to provide. Health care in-

stitutions should establish and follow procedures to verify the credentials of physicians and other health professionals, assess and improve quality of care, and review appropriateness of utilization.

- Health care institutions should have policies and practices that support the process of informed consent for diagnostic and therapeutic procedures and that respect and promote the patient's responsibility for decision-making.

- Health care institutions are responsible for assuring confidentiality of patient-specific information. They are responsible for providing safeguards to prevent unauthorized release of information and establishing procedures for authorizing release of data.

- Health care institutions should assure that the psychological, social, spiritual, and physical needs and cultural beliefs and practices of patients and families are recognized and should promote employee and medical staff sensitivity to the full range of such needs and practices.

- Health care institutions should assure respect for and reasonable accommodation of individual religious and social beliefs and customs of patients whenever possible.

- Health care institutions should have specific mechanisms or procedures to resolve conflicting values and ethical dilemmas among patients, their families, medical staff, employees, the institution, and the community.

Organizational Conduct

- The policies and practices of health care institutions should respect the professional ethical codes and responsibilities of their employees and medical staff members and be

sensitive to institutional decisions that employees might interpret as compromising their ability to provide high-quality health care.

- Health care institutions should have policies and practices that provide for equitably administered employee policies and practices.

- To the extent possible and consistent with the ethical commitments of the institution, health care institutions should accommodate the desires of employees and medical staff to embody religious and moral values in their professional activities.

- Health care institutions should have written policies on conflict of interest that apply to officers, governing board members, physicians, and others who make or influence decisions for or on behalf of the institution. These policies should recognize that individuals in decision-making or administrative positions often have duality of interests that may not ordinarily present conflicts. However, they should provide mechnaisms for identifying and addressing conflicts when they do exist.

- Health care institutions should communicate their mission, values, and priorities to their employees and volunteers, whose patient care and service activities are the most visible embodiment of the institution's ethical commitments and values.

AHA Resources

These guidelines identify the major areas affecting the ethical conduct of health care institutions. It would be impossible for one advisory document to detail all of the factors and issues relating to each area. Additional information

and guidance is available in the following AHA publications:

Cost and Compassion: Recommendations for Avoiding a Crisis in Care for the Medically Indigent
Guidelines on Advertising by Hospitals
Guidelines on Discharge Planning
Guidelines on Disclosure of Financial and Operating Information by Health Care Institutions
Guidelines on Establishment of an Employee Grievance Procedure
Guidelines on Hospital Committees on Biomedical Ethics
Guidelines on Institutional Policies for Disclosure of Medical Record Information
Gudelines on Resolution of Conflicts of Interest in Health Care Institutions
Guidelines on Role and Functions of Hospital Medical Staff
Policy on Health Planning
Policy on Imperatives of Hospital Leadership
Policy on a Patient's Bill of Rights
Policy and Statement on Continuity of Care for the Chronically Ill and Disabled
Policy and Statement on Human Resources Management in Health Care Institutions
Policy and Statement on the Patient's Choice of Treatment Options
Policy and Statement on Quality Assurance in Health Care Institutions
Technical Advisory Bulletin on the Caring Climate in Hospitals
Technical Advisory Bulletin on Verification of Physician Credentials
Values in Conflict: Resolving Ethical Issues in Hospital Care

APPENDIX D

AMERICAN HOSPITAL ASSOCIATION

Guidelines

HOSPITAL COMMITTEES ON BIOMEDICAL ETHICS

This guideline document is intended to provide general advice to the membership of the American Hospital Association, as approved by the General Council.

Introduction

The growth of medical knowledge and the rapid expansion of medical capabilities and technology have generated unprecedented opportunities and challenges in the delivery of health care. At the same time, this growth and expansion have created increasingly complex ethical choices for physicians, health care professionals, patients, and the families of patients. Recent efforts to clarify biomedical ethical issues on the institutional level have focused on the use of hospital biomedical ethics committees. Such committees, sometimes called "ethics committees," "human values committees," "medical-moral committees," or "bioethics committees," hold promise for identifying the ethical implications of these problems and their possible resolutions, if they are established

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The American Hospital Association's General Council created a special Committee on Biomedical Ethics in 1982. This multidisciplinary committee prepared these guidelines as part of its charge to assist hospitals in developing institutional processes to deal with the educational and decision-making challenges presented by biomedical ethical issues. These guidelines were approved by the AHA General Council on January 27, 1984.

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with a clearly defined purpose and an understanding of their capabilities and limitations.

Institutional ethics committees are one of several approaches to address medical ethical matters. If an institution chooses this approach, the following guidelines may assist in determining the organization, composition, and function of these committees. Because such committees are relatively new and largely untested, the guidelines are not intended to be prescriptive or directive.

Functions

Although institutional ethics committees may have one or more functions, they seem particularly suited to: (1) directing educational programs on biomedical ethical issues, (2) providing forums for discussion among hospital and medical professionals and others about biomedical ethical issues, (3) serving in an advisory capacity and/or as a resource to persons involved in biomedical decision making, and (4) evaluating institutional experiences related to reviewing decisions having biomedical ethical implications. Ethics committees should not serve as professional ethics review boards, as substitutes for legal or judicial review, or as "decision makers" in biomedical ethical dilemmas. An ethics committee should not replace the traditional loci of decision making on these issues.

Educational programs on biomedical ethics issues serve to heighten awareness and provide guidance on identification of cases where ethical problems may arise. Such programs may be offered to medical staff, the hospital staff, and the community. Forums for the discussion of these issues serve similar purposes by providing an opportunity for physicians, nurses, administrators, trustees, clergy, ethicists, and others to consider and discuss a number of diverse perspectives.

The use of ethics committees in an advisory role to assist physicians, other health care professionals, and patients

and their families to make decisions when confronted with dilemmas is probably their most complex function. Ethics committees often may make recommendations at the request of an attending physician, another hospital professional closely connected with the case, the hospital administration, and the patient or the patient's family. Access to the committee should be open to all those involved in patient care decisions. Hospitals should design and implement systems to bring to the committee's attention certain kinds of issues and to address similar issues in a reasonably consistent manner.

Composition

The members of an ethics committee should be selected in keeping with its objectives and represent a range of perspectives and expertise. It may be multidisciplinary and may include physicians, nurses, administrators, social workers, clergy, trustees, attorneys, ethicists, and patient advocates (representatives). Hospital legal counsel should be available at the request of the committee, and legal review of its recommendations may be necessary.

To be most useful and effective, an ethics committee should be a standing committee, and its members should be approved by the appropriate authority within the institution. This structure provides continuity and enhances the credibility of the committee. It also provides an opportunity for the committee to develop an understanding of the permissible range for discretion and latitude within which biomedical ethical decisions may be made. The committee should meet regularly and whenever necessary to provide advice and recommendations. As a general rule, no one who is personally involved in the case in question should serve on the committee while the case is being considered.

Deliberations

Issues that may be brought to an ethics committee acting in an advisory capacity should relate to patient care.

If a recommendation is made by the committee, it should be provided as appropriate to the physicians, nurses, and other health care professionals involved in treatment, and should be offered to the patient and the patient's family or other surrogate.

The confidentiality of patient information and the patient's privacy should be respected. The circumstances under which documentation of the committee's recommendations should appear in the patient's medical records should be determined by each institution with the advice of legal counsel.

The manner in which the committee considers an issue or a particular case should depend on the individual circumstances. The committee may review and discuss materials submitted to it, or it may meet with the health care team involved and others as needed, including persons acting on the patient's behalf.

Conclusion

Each institution should take the steps necessary to implement suitable mechanisms that will reasonably provide for sound decision-making practices and for responsible and timely assessment of medical and ethical issues.